Last Word

Whatever happened to AIDS activism? Stephen Gendin dares his comrades to bite the hand that feeds ‘em.

October 1, 2000 By Stephen Gendin

It was a beautiful night last September at San Francisco City Hall. Just renovated, the building positively sparked with its newly cleaned marble and gilded pillars. Strolling through its palatial halls, listening to a 12-piece tuxedoed string orchestra, I felt like royalty as I went from one tasting table to the next, sampling morsel after tasty morsel. There was the oysters-on-the-half-shell bar, the lobster bar, and the sushi bar. Everywhere I looked there was food. And where there wasn’t food, there was liquor. More than a dozen different local wines from Napa and Sonoma counties were being offered by handsome, courteous staff. The crowd—hundreds of us—chatted merrily as we moved from the roast beef-carving station to the table decked out in hors d’oeuvres and on to the next delicacy.

The wealth and excess started to make me nauseous. After all, the event was DuPont Pharmaceutical’s annual community reception at the fall’s big AIDS shindig—The International Conference on Antimicrobial Agents and Chemotherapy (ICAAC)—and the guests were a who’s who of community activists, doctors, researcher scientists, and drug company wholesale salespeople. Everyone was there to share the splendor. I was told by a representative of a competing company that DuPont had ponied up a million-dollar donation to the city to rent the building, and the catering bill cost another fat chunk of change. As a special gift, as guests were leaving; we got a bottle of our favorite wine; the president of Napa Wine Association was on hand to help make the selection that was right for you.

Such high-end events are common in the world of AIDS. I’ve been flown to Nantucket by Glaxo-Wellcome, and put up at the best hotels on the beach in Santa Monica, thanks to Agouron. (I missed the gala where everyone in attendance was slipped a hundred dollar bill just to say thanks for coming.) There isn’t a drug company around that doesn’t lay on the largesse. And I’m only an activist (who also owns and runs Community Prescription Service, a mail-order AIDS pharmacy). The doctors get treated 10 times better, free facials, massages, and other perks during meetings.

The DuPont event struck me as particular sickening because the same noshing activists had not so long ago, protested DuPont’s decision to price its NNRTI drug, Sustiva, at near-protease-inhibitor prices. That announcement caused a groundswell of community unrest, complete with sit-ins and other actins. Yet, here we all were, enjoying the fruits (and fish and fowl) of DuPont’s decision to

jack up the price. The one question on no one's well-fed lips that evening was: How much did this one event cost of Sustiva? I had to wonder if HIVers were paying an extra $5 for their meds so that I could California rolls.

So why do I go to these events? Well, everyone goes. It's a good place to catch up with all my treatment activist friends. And it an opportunity to see places I'd never be able to afford on my won. Who knows how much time I have left on this planet—don't I deserve to enjoy myself? And if I don't go, they'll just give slot to someone else.

The fat is, I blame the drug companies for this excess far less than I blame myself and other activists. The phrama folks are business people; they are just following the rules: Keep the critics happy; pamper the people who are vital to your interests. That's the way the game is played in the auto, banking, and travel industries. Unfortunately, it's up to us activists to keep the game in check, to remind everyone that there's a higher purpose to life than making a buck. If we all refused to attend, these junkets, would stop or at least be modest. We'd stay at the Holiday Inn instead of the Ritz.

It's hard to write this column because I know is spells the end of my trips: Don't bite the hand that feeds you. I've considered scrapping it a dozen times because I don't want to give up these deluxe meetings. And that's the point. We're meant to be indebted to these companies, think of them as our friends—or at least not out adversaries. They know that its human nature to think fondly of people who wine, dine, and otherwise treat you well.

These days, my friend and I often mourn the loss of activism. Everyone we know is still doing AIDS work, but our involvement has become institutionalized. We aren't volunteers anymore: we're professionals. AIDS is a 9-to-5 JOB. It disgusts me to see what I've become. Ten years ago we would never have accepted such gifts and graft from drug companies. Now we've come to count on it. But nothing's free, and whether we know it or not, we're paying the price with our lives.

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